



COMPARING METHODS USED TO TRANSLATE CONSENT FORMS FOR LIMITED ENGLISH PROFICIENT SPANISH PARTICIPANTS

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Editorial/Opinion

Coping with death of a child

Pain, prayer, food, comfort, privacy, pain, anger, hurt



Wake up, growth is here

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GRICELDA ZAMORA

ARIZONA

SPRING 1999

13 YEAR OLD PATIENT

INFORMED CONSENT

- Nuremberg Code 1947
 - Hippocratic Oath (470 and 360 BC): physician-patient relationship
 - Percival Code of Medical Ethics (1803): addressed innovative therapies
 - Beaumont experiment (1833): focused on nontherapeutic research
 - Introduction to the Study of Experimental Medicine (1865): focused on the scientific method and therapeutic research
 - The Guidelines of Reich Circular (February 28, 1931): German document that protected human and animal rights through experimental studies
- Declaration of Helsinki in 1964

INFORMED CONSENT



Belmont Report 1974

Identified 3 ethical principles that should be followed when conducting research that includes human subjects

Beneficence, Justice and Respect for Person

- Informed consent was created as an application of these principles



Informed Consent Process

Information
Comprehension
Voluntariness

LEP SPANISH PARTICIPANTS

- LEP: Limited English Proficiency
- US Public Health Service Investigators led the Guatemala Study 1946
 - Main goal was to study the progression of STD and determine the effective doses for medication
- A study explored the informed consent process between surgeons and LEP Spanish patients (Patel et al. 2016)
 - Surgeons admitted to using their limited language skills
 - Using hospital staff members and family members to interpret

RESEARCH GAP

- Translational errors (Brelsford et al (2018))
 - non-equivalent terms, omission of important terms, and changes to overall meaning of the study
- Translation does not equate comprehension (Lee et al. 2017) (Leyva et al. 2005)
 - 22% comprehension with English instructions vs. 29% comprehension with Spanish instructions
- The effects of cultural beliefs on comprehension (Lie et al, 13–22.)
 - LEP Spanish patient believed that insulin would lead to blindness and used Mexican remedies for his diabetes

RESEARCH AIMS

- DESCRIBE AND COMPARE THE METHODS USED TO TRANSLATE WRITTEN CONSENT FORMS FOR LEP SPANISH PARTICIPANTS
- EXPLORE THE ROLE OF HEALTH LITERACY IN TRANSLATION
- EXPLORE THE ROLE OF CULTURAL APPROPRIATENESS

THEORETICAL FRAMEWORK

Intersectionality Theory

Multiple social identities like (race, class, gender) influence the way a person experiences a certain phenomenon.

LEP Spanish participants' social identities like (class, education, race) shape their informed consent process.

TRANSLATORS

Four Translation Services

1. UR Interpreter Services
2. John Hopkins Centro Sol
 1. Material review
 2. Translation review
3. Freelance Translation
4. Private Translation Service

- Inclusion criteria:
 - History of translating English consent forms into Spanish consent forms
 - Spanish translators
 - Experience with translating IRB approved written consent forms
- Exclusion criteria:
 - No prior history of translation from English consent forms into Spanish consent forms
 - Not Spanish translators
 - No experience with translating IRB approved written consent forms




METHODS

- INTERVIEWS

- Semi structured phone interviews (30-60 minutes)
- 5 participants
- IRB Exempt Protocol Approval
- Interviews were recorded and transcribed

- CODING

- First level of coding included: in-vivo coding, descriptive coding, process coding and pattern coding
 - Second cycle of coding included: thematic coding
 - Identify the most frequent codes and then compared it across translation services
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RESULTS

- Description of the translation process
 - stay true to original document, referencing Spanish documents, and collaboration
- The role of health literacy in translation
 - simple language, and experience with medical system
- The role cultural appropriateness in translation
 - know the audience, and community involvement

RESULTS

Translation Process

■ **Theme: Stay True to the Original**

- All translators emphasized this throughout their interview
- *UR Interpreter Services: “We're not just going word for word for word, but we're going meaning for meaning, and that what they wrote, while it was all well and good and beautiful when it was in one language it does have to be deconstructed, and then reconstructed in another.”*

■ **Theme: Collaboration**

- Private translation services described their process as a one-person operation.
- UR Interpreter services, freelance translator and John Hopkins Centro Sol stated they translated documents as a team
 - Included researcher, colleagues and specialist in other fields.

RESULTS

Translation Process

- **Theme: Referencing Spanish Documents**
- Occasionally, the private translation service used various bilingual dictionaries. But stated they did not use them frequently because of 50 years of experience translating document.
- Other translation services relied on bilingual dictionaries and consent forms written in Spanish to understand how concepts are explained
- UR Interpreter Service: “In English, we're blaming the actual defect itself, the actual hole that is present in that septum. Whereas, in Spanish we would say *communication interventriculaire*, which is referring to the same type of concept. However, it's really referring to a communicational or mixing of the deoxygenated and oxygenated blood between those two chambers of the heart. It's two ways that the two different languages are describing the same process or the same concept.”

RESULTS

Health Literacy

- **Theme: Simple Language**
- All translation services emphasized using simple language in consent forms when possible
- *John Hopkins Centro Sol: "Instead of saying something like "120 days", saying "four months". Sometimes it's okay to be less exact in order to be simpler because when someone says "120 days" you're thinking in your head, "Okay. 120 divided by 30," and doing the math in your head. It's more exact but you're causing people to have to stop thinking about what they're reading to do a little bit of math in their head and then come back to it."*
- **Theme: Experience with Medical System**
- Only UR Interpreter Service and JH Centro Sol stated the participants' experience with the health care system influenced their understanding of the consent
- *John Hopkins Centro Sol: "If they are indigenous, they may have had really negative experiences within the health system in their home country. They may have also had negative experiences in the health system here in the U.S. because they don't speak English and because they don't necessarily speak Spanish well. People can often be really, really wary. Especially if you're doing recruitment in a clinical setting."*

RESULTS

Culture Appropriateness

■ Theme: Know the Audience

- All the translators stated they gather information about the intended audience, and this shaped their word choices
- Private translator:
 - *Tú*
 - *Usted*
 - *Vos*

■ Theme: Community Involvement

- John Hopkins Centro Sol was the only program that involved LEP Spanish community members in the process of reviewing translations.
- *John Hopkins Centro Sol: "Anything we translate we always try to get the Latino Family Advisory Board's feedback on it because they just really do a great job of pointing out words. Like words that we use that maybe they wouldn't use."*

GUIDELINE FOR TRANSLATING CONSENT FORMS FOR LEP SPANISH PARTICIPANTS

Effective Translation Methods to Improve LEP Spanish Participants' Comprehension		
To improve accuracy	Stay true to the original document	<ul style="list-style-type: none"> - Multiple cycles of editing, proofreading, and writing - Ask researchers questions for clarification - Pilot test translations with a Spanish speaker
	Reference Spanish documents (consent forms and dictionaries)	<ul style="list-style-type: none"> - Understanding terminology, phrasing, tone used consent forms - Gain an understanding of how concepts and diseases are explained in Spanish countries - Try to minimize the use of specialized and complex terminology
	Collaboration	<ul style="list-style-type: none"> - Have translations reviewed by other translators that have experience with target audience - Collaborate with researchers to define and generate explanations for certain concepts - Seek the help of specialists with specific topics and to review the translation

Table 1: Identifies methods translators can incorporate into their process to improve the translations, and comprehension levels of LEP Spanish participants

GUIDELINE FOR TRANSLATING CONSENT FORMS FOR LEP SPANISH PARTICIPANTS

To improve health literacy	Simple language	<ul style="list-style-type: none">- Use simple language when possible- Reference CDC Clear Communication Index and Clear Communication Guide- Avoid using different terms for the same concept- Be repetitive in word choice
	Experience with the medical system	<ul style="list-style-type: none">- Have an awareness of the variety in LEP Spanish population- Understand the Spanish fluency level with vary- Be aware that many participants have negative experiences with the medical system

Table 1: Identifies methods translators can incorporate into their process to improve the translations, and comprehension levels of LEP Spanish participants

GUIDELINE FOR TRANSLATING CONSENT FORMS FOR LEP SPANISH PARTICIPANTS

To improve cultural awareness	Know the audience	<ul style="list-style-type: none">- Gather information about which Spanish countries are present in the target audience- Learn about the different Spanish dialects- Incorporate regional words that correspond with the intended audience in the translations- Consider rephrasing certain parts if there is a concern about the target audience misinterpreting or being offended by the section- Consider how the audience would view the translation
	Community involvement	<ul style="list-style-type: none">- Have LEP Spanish community members review the translation- Incorporate colleagues that have experiences with community in the translation and review process

Table 1: Identifies methods translators can incorporate into their process to improve the translations, and comprehension levels of LEP Spanish participants



GRACIAS



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